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RE: Responses to The Severe Fatal Impairment Abortion (Amendment) Bill 2021
Clause 1: Amendment of abortion on the grounds of disability

Below is my written submission to the committee regarding the above bill:

I am a consultant Obstetrician, fetal medicine specialist and Gynaecologist. I am also co-chair of the UK National Abortion Care Taskforce. I have spent the past 30 years of my career in assisting women with diagnosis of fetal anomalies, being involved in the counselling and explanation after prenatal investigations and in supporting women (whether they opt to continue the pregnancy or to have a termination). I am concerned by the the potential for the Severe fetal Impairment Bill to do enormous harm to the women and families who are faced with a pregnancy affected by fetal anomaly.

1. Terminations of pregnancy for fetal anomaly (TOPFA) – abortions performed under s1(1)(d) of the Abortion Act 1967 or ‘Ground E’ - represent just 2% of all terminations in England and Wales. In recent years, the number of TOPFAs has risen principally due to technological developments in prenatal screening and diagnosis as well as increased maternal age, which have led to a growing number of fetal anomalies being identified prenatally.
2. Second trimester or mid-gestational ultrasound screening for fetal structural abnormalities is very different from first trimester screening which is undertaken for specific major fetal anomalies and fetal trisomy at between 11-14 weeks gestation.
3. In contrast, second trimester ultrasound screening is undertaken at 19-22weeks and covers a wide range of potential concerns including anatomy of fetal organs (brain, heart, bowel, kidneys etc.), functioning of different organ systems (hydrops, anaemia, movement etc.) as well as fetal growth. These conditions encompass a very wide range of disease severity and typically require specialist care in tertiary centres. In 2019, only 10% of Ground E abortions occurred prior to 13 weeks’ gestation – reflecting the stage at which most fetal abnormalities are detected.
4. When a fetal condition is suspected or diagnosed, the woman is typically referred to a specialist tertiary centre to have further investigations as required to enable provision of

personalised information and support. This referral typically occurs within seven to ten days but by this point the pregnancy may already have reached 23 weeks gestation.

5. The range of fetal health conditions vary from anatomical, nutritional, cardiovascular, immune, viral, chromosomal and genetic. The investigations required to formulate an accurate diagnosis and evaluate prognosis is complex in terms of the type, timing and interpretation of tests.
6. Women would usually be offered invasive prenatal diagnosis (such as amniocentesis) which carries a risk of miscarriage and they should be given time to consider whether they want this investigation. Even when such a procedure is undertaken, the initial genetic results - polymerase chain reaction (PCR) chromosomal array - will take up to 2 weeks to be returned. Furthermore, the increasing use of chromosomal arrays and exome sequencing genetic analysis has resulted in several 'tiers' of interpretation of results ranging from possible clinical significance, probable clinical significance to a pathological clinical result. Typically, such results require a consultation with specialist Clinical Geneticists for the parents to understand and process this information – and then consider the options of expectant management versus termination of the pregnancy.
7. A diagnosis of major fetal problems and the decision to undertake a late termination is always reviewed in weekly fetal medicine multidisciplinary team (MDT) meeting to ensure cross-speciality agreement.
8. Testing, and the interpretation of the results of those tests, which can be extremely complex, therefore requires a time period beyond 24 weeks in many cases. In addition to further diagnostic tests, women and their partners must have an appropriate period of time to reflect on the important decision which is theirs to make within the constraints of the law.
9. A consequence of restricting the term limits in these cases would be two-fold. Firstly, it is unlikely the necessary testing and interpretation and diagnosis could be achieved within this period. This would essentially force women and their partners to make a decision on whether to continue or terminate their pregnancy without the full information required. Secondly, it would leave very little time to properly reflect on the results and the information that they do have. A likely consequence would be that otherwise wanted pregnancies would be terminated before 24 weeks under a different ground, where the anomaly may not be severe, but due to a lack of information and the time-pressure the parents would be placed under. Allowing abortion for severe fetal impairment without time limit, as is currently the case, ensures that the time is given for the most fully informed and considered decision to be made.
10. As medical practitioners, we must also recognise the limitations of existing diagnostic tools. The truth which we have to share with pregnant women and their partners is that we cannot know for certain what the outcome of a particular pregnancy will be – we can simply

interpret the evidence so as to provide a likelihood of certain events. This includes intrauterine fetal demise, further worsening of the fetus's condition prior to birth, impacts on the woman's health, and undetected sequelae presenting subsequent to birth. As a result, there are relatively few examples of diagnosed abnormalities where clinicians can tell a woman definitively that there is absolutely no chance of her fetus surviving. The current law recognises this difficulty, and provides Registered Medical Practitioners with the ethically necessary ability to certify abortions where the ultimate outcome may be either fetal demise or a serious, irreparable disorder that results not in death but an unknown period of suffering. The women and partners we support often report making the decision to end a pregnancy not because fetal demise is certain, but because they do not want their much-loved unborn child to live in such pain.

11. At the same time, underpinned by a woman's ability to consent or opt out of aspects of antenatal care, we treat many women who know they wish to continue their pregnancy to term and thus opt out of screening or diagnostic testing. Further, there are women who continue with their pregnancies subsequent to the diagnosis of a fetal abnormality. According to the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS), which collects information from every region in England, in 2018 (the latest year for which figures are available), 73.5% of congenital abnormalities were diagnosed antenatally, and a total of 73.4% of all fetuses and babies diagnosed with a congenital abnormality resulted in a live birth. When considering the case of Down's syndrome, only 56% of diagnoses were made antenatally, with 44% of women opting out of screening and/or diagnosis. There were 722 live births of children with Down's syndrome (46% of the total), compared to 799 TOPFAs. As a testament to the complexity of diagnosing likely outcomes, 41 of these pregnancies ended in post-20 week miscarriage or stillbirth – a rate of 57 per 1000 live births (excluding TOPFA outcomes) of children with Down's syndrome, compared to a population rate of roughly 6 per 1000 live births. That is to say that decisions about antenatal care are complex and driven by a woman's personal decisions about her health and wellbeing – whether or not she and her partner wishes to continue a pregnancy, but also whether or not she wishes to engage with national screening programmes or diagnostic tests. As a result, simply considering the outcomes for pregnancies diagnosed antenatally does not adequately reflect the choices made by women during their pregnancies.
12. The consequences of any restriction to s.1(1)(d) of the abortion act can be seen in other nations where TOPFA is not permitted. A number of testimonies were articulated clearly in the Supreme Court judgment on the 2018 Northern Ireland Human Rights Commission judicial review appeal. These cases reveal the circumstances women would be forced to endure should s.1(1)(d) of the Abortion Act 1967 be removed or restricted. In both of the

cases referenced in the judgement, women in Northern Ireland were forced to carry pregnancies with a fetal anomaly. In the first, a 20-week scan revealed a severe bone anomaly. The judgement states that “After being refused a termination, at 35 weeks she went into labour and gave birth to a girl, whose appearance indicated that her heart had probably stopped beating two or so days earlier. During and after the pregnancy, Mrs Topley faced the ordeal of others congratulating her on her pregnancy or asking about the baby.” In the second case, there was another diagnosis of fetal anomaly and termination was refused. The judgement states that: “She became even more depressed and ill as a result, and thought of committing suicide. She knew when her baby died, but it was five days before she was induced to give birth. During that period the dead baby released meconium which fills the womb and suffers decay, an experience for which no one had prepared her and her husband and which remains seared in her mind.”

13. We should also consider the difficulty in diagnosing whether a fetal anomaly is “severe” or “fatal”. The Republic of Ireland recently passed the Health (Regulation of Termination of Pregnancy) Act 2018. In the Act, it considers a ‘fatal fetal anomaly’ to be “where two medical practitioners are of the opinion formed in good faith that there is present a condition affecting the foetus that is likely to lead to the death of the fetus either before, or within 28 days of, birth.” A recent paper titled ‘The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland’ examined the findings of coronial inquests into stillbirths and neonatal deaths for fetuses and neonates which had died following diagnosis of a congenital abnormality. The study concludes that “less than half of the congenital anomalies could be classified as an FFA [Fatal Fetal Anomaly]; however, all were fatal. This acknowledges the complexity of these cases. In isolation, the congenital anomaly may not be fatal, but combined as multiorgan system anomalies, it is. Knowledge is required to inform clinical practice and counselling of parents who receive such a diagnosis.” In these cases, in the Republic of Ireland as a direct result of the restrictive legal provision which does not provide for true medical assessment of the impact of severe fetal abnormality, women are forced to continue with a pregnancy that ultimately results in stillbirth or fatality within 28 days, or to travel to Great Britain in order to have a termination.
14. In a hypothetical situation of a woman who is denied an abortion (for example, for a fetus with Down’s syndrome), she will then have to continue to term and deliver. In the event of an obstetric emergency (such as cord prolapse) which requires an emergency Caesarean section in order to avoid stillbirth, she can currently decline this if she wishes, in the knowledge that she will then not have to deliver a live born with Down’s syndrome. Existing law is very clear that we cannot insist on her having a Caesarean in order to save the life of the unborn or to prevent permanent injury to the unborn, or even to protect the life of or prevent serious injury to the woman, as this would be an assault (St George’s Healthcare

NHS Trust v S (1997)). The basis of this law is that a woman's right to privacy and bodily autonomy are not diminished by virtue of her being pregnant. It relies upon the understanding, well-established in case law and in guidance for practising obstetricians, that the fetus does not have legal rights or personhood. The logical extension of this bill, which would endow the fetus with rights reserved for persons under the law, is to place the rights of the fetus on an equal footing with that of the pregnant woman, which is unacceptable, leading to the possibility of enforcing medical treatment - entirely unrelated to abortion - on a woman against her wishes.

Our role as advocates for women should be to argue the case for trusting women and respecting their autonomy. As fetal medicine specialists and as obstetricians, we provide information, explanation and support to women and their partners. The support we provide then becomes support for women in the decisions which they make. Our counselling must be non-directive and non-judgemental. We know that women faced with any diagnosis of serious fetal anomaly will make different decisions based on their own personal, cultural and social values. Therefore, the provisions of the law should remain unchanged, allowing the expert medical teams to continue to care for women through these extremely complex personal, ethical and moral decisions which they must be allowed to make.

Yours faithfully,

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